

August 1991

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# Clinical Center News

## Bone Marrow Unit To Begin Construction

This fall, construction will begin on the new \$4 million bone marrow unit. The unit will occupy the space previously used by the cardiac surgery service on 2W.

Development and planning of the unit is a collaborative effort among the National Heart, Lung, and Blood Institute (NHLBI), the Division of Engineering Services, and the Clinical Center. The primary functions of the unit will

include care of patients with hematological disorders and those undergoing bone marrow transplantation.

"Although NHLBI will be the lead institute, it is a research facility available to other institutes and researchers," says NHLBI Deputy Clinical Director for the Division of Intramural Research Dr. Arthur Nienhuis. "It will serve a function that cuts across

boundaries."

"We have had a cohesive team that has worked well under time pressures. Everybody realizes this is an exciting line of research and is extremely motivated," adds Clinical Center Deputy Executive Officer for Operations Lawrence Eldridge.

"There was a need to provide a facility for research related to gene therapy and an appropriate

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## Gene Therapy: Working With The Department of Transfusion Medicine

By Sue Kendall



To a sick little girl, it must seem tiresome and bewildering. She comes to the Clinical Center from her home in Ohio, she has blood taken from her arm, and later has some "stuff" put back into her arm. Then she goes home until next month, when the process begins all over again. All she wants is to feel better. What she's too little to understand is that she's a part of medical history.

Last September, in performing

*GENE THERAPY* Continued on Page 4

# *Love Letters...*

## Praise for CC staff

To my friends at NIH,

Thanks for the flowers and all your care and concern. The opportunity to participate in a marrow donation is a very rewarding experience. I would not hesitate for a second to participate again.

It has been a pleasure donating platelets and white cells over the years. I'm glad I could be a candidate in the marrow program too. All people associated with each program have been terrific.

Special thanks to Robyn for being my champion through the

bone marrow donation process. Your emphasis on donor comfort and requirements speaks highly of you and the program.

Thanks again to all of you,

Dennis

## *Patient Education Perspectives*

*Wendy Schubert, Sc.M.*

*Office of Clinical Center Communications*

New Patient Education Publication Available:

Patients scheduled for needle localization of breast lesions now have access to a booklet that explains the procedure. Catherine Chow, M.D., Ella Laseinde, R.T., and Victor Wright, R.T., of the Diagnostic Radiology Department collaborated to develop *Needle*

*Localization of a Breast Lesion.* The booklet defines needle localization and explains what happens before, during, and after the procedure. For copies of this booklet, contact the authors.



This year's Patient Emergency Fund auction, held in April, raised \$16,400. Janice Weymouth, chair of the auction, presents a check to Chief of the Social Work Department Jim Sayers. The auction raises funds to help CC patients and their families meet emergency expenses.

## *CC News*

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Editorial

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*Clinical Center News* is published monthly by the Office of Clinical Center Communications, Colleen Henrichsen, chief, for employees of the Clinical Center, National Institutes of Health, Department of Health and Human Services.

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Deadline for submission is the second Monday of each month.

# 2J Staff Race In Support Of Cancer

It is often said that Clinical Center employees go the extra distance for their patients. This has never been so true as it was recently when a group of dedicated Clinical Center employees from 2J surgical intensive care unit took an extra step—or two—or 5 kilometers.

Over forty 2J doctors, nurses, respiratory therapists, recreational therapists, and messengers from the patient escort service ran and walked in the 2nd annual Race for the Cure in June.

The Race for the Cure is a 5K run and a 1-mile fun run/walk organized to raise money to fund breast cancer research, treatment, and education. According to *Runner's World*, the race is "a sporting event with a mission: the cure and control of breast cancer."

"Ninety percent of our patients here are cancer patients. We see the effects of cancer everyday," says Paula Muehlbauer, R.N., who

organized the 2J runners. "We wanted to get involved and support cancer research."

"It was really Jody's [2J head nurse Jody Becker] idea," she says. "She saw the entry form, gave it to me, and asked me to get a group organized."

NIH had over 200 participants in the race and the 2J runners constituted the largest NIH group.

Although the runners trained individually, the race was a team effort. The day before the race, runners and walkers had a pasta lunch—what they refer to as a carbo-loading lunch.

"It was really fun getting people into it. It was a real team-building effort," says Muehlbauer.

The day of the race, the 2J group met at Old Ebbitt Grill in Washington, a central location for the race, where they had agreed to gather afterward for fun, food, and drink.

Most of the NIH people

walked, but they walked the entire 5 kilometers. Of the 2J runners, the men's first place finisher was Jai Balkissoon, M.D., and the women's first place finisher was Muehlbauer.

"It was hot," says Mary Miller, R.N., with a laugh. "A wheelchair passed me."

"It was really hot, but it was a really good course," adds Muehlbauer. The course started at Freedom Plaza and wound around the Capitol.

"It was a lot of fun. People were cheering for you—and there was a great expo and free food at the end!" exclaims Muehlbauer. "We would like to make it an annual event."

"There was a wide cross section of society—young, old, runners, walkers, and handicapped people," says Miller. "It was great fun. I'd love to do it again!"

The first Race for the Cure was in Dallas in 1983, sponsored by the Komen Foundation. It was, and continues to be, organized by Nancy Brinker, a Dallas socialite who lost her sister, Susan B. Komen, to breast cancer and who battled breast cancer herself. Brinker established the Komen Foundation in 1982. By 1990, the foundation had raised more than \$8 million for research, education, screening, and treatment for breast cancer. The foundation provides a national toll-free hot line, 1-800-IM-AWARE, that women can call to get information about breast cancer and good medical care. ■



(L to R) Myroulla Koyzis, R.R.T., Helen Pogrebniak, M.D., Magda Sgagias, and Bea Pass enjoy themselves in Washington, D.C., during the Race for the Cure.

one of these apparently simple infusions, the Clinical Center's Department of Transfusion Medicine (DTM) used its resources and expertise to carry out the cutting-edge gene therapy protocol, developed by Dr. W. French Anderson of the National

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Heart, Lung, and Blood Institute and Drs. R. Michael Blaese and Kenneth Culver of the National Cancer Institute. A second child began the protocol in January. Says Dr. Harvey Klein, chief of DTM, "We were very enthusiastic about being a part of this program. We knew we had the technology that would benefit it."

DTM prepared more than one billion genetically repaired white blood cells that were transfused into the bloodstream of the 4-year-old girl who has ADA deficiency, a lethal and rare hereditary disorder in which cells lack a gene that produces an enzyme essential to the proper functioning of the immune system. It is the same disease that afflicted the "Boy in the Bubble," who survived to age 12 by living in a completely sterile environment to avoid infections.

Not only did DTM collect the cells from the young girl, it also assisted with the behind-the-scenes repairs on the cells to get them ready to be infused. Gene

therapy involves fixing these defective cells by inserting into them the gene they lack and then infusing the repaired cells back into the patient. Although cell repair can be done in a regular research laboratory, Anderson and Blaese needed to grow large quantities of the cells, repair them, and place them back into the patient without introducing any infections. Enter DTM.

When the little girl arrives at the Clinical Center for her monthly treatment, she goes to DTM where she "donates" a unit of blood. About a billion white cells are then separated out so the missing gene can be inserted, and the remaining blood cells are infused back into the patient. If the child were larger, she could be hooked up to a machine that would automatically draw the blood, separate out the white cells, and reinfuse her blood, a process called apheresis. But with a small child, the "low-tech" method is simpler, faster, and works just as well.

The cells are drawn from the child in one area of the department, carried about 20 yards to a laboratory in another area, treated, grown, concentrated, and sent to the patient's bedside in a blood bag, "just as you would issue a blood transfusion," Klein explains. The cycle takes about two weeks. When the child returns for the infusion of the treated cells, all she has to do is lie quietly while the grayish mixture drips into her veins, just as if she were receiving a transfusion of her own blood.

"That part is very easy for the patient," says Klein. "The real difficult part is for the people handling the cells. Dr. Culver and my staff, for whom I have only the highest praise, really worked around the clock to prepare for our

part in this," he says.

The mechanism for repairing the defective cells by carrying the missing gene into them is called a vector (see box). The vector is produced in a commercial high-tech laboratory under Anderson's supervision and is sent to DTM in a container, much as any lab reagent would be. DTM then uses a time-tested open system of plates and wells to combine the vector with cells taken from the patient. The mixtures are placed in incubators to allow the vector to carry the gene into the cells under sterile conditions, a process called "treating" or "transducing" the cells.

Although the process of treating the cells sounds simple, "it is very labor-intensive, meticulous work that goes on seven days a week," and requires at least two full-time laboratory

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DTM is working to automate the cell-handling and transfusion technology to the point where it can be exported to other hospitals. "Right now, it is very difficult, very time consuming, and very expensive," says Klein. "There aren't many institutions that can

mobilize the resources to do it the way it's being done here," he adds. "We're taking technology that we work with in the transfusion world and marrying it to very state-of-the-art laboratory techniques so that they're more practical to use in humans."

**"We're taking technology that we work with in the transfusion world and marrying it to very state-of-the-art laboratory techniques so that they're more practical to use in humans," says Klein.**

A major goal is to close the system so cells are grown, treated, and infused back into the patient all in one set of transfusion bags. This would ensure easier handling of the fragile engineered cells. The current system of using plates and wells is certainly effective, but a closed system would virtually eliminate any chance of contamination by reducing the cells' exposure to air or other lab hazards.

DTM has also developed techniques for labeling these bags of cells, with an eye toward exporting the technology. Since the Clinical Center is currently treating only two patients, labeling isn't a problem. However, should gene therapy become widely used, there must be a method for ensuring that each patient receives his or her own cells. A mistake could have disastrous results.

Based on findings of blood

studies done over the last year, DTM researchers have targeted additional areas to improve the technology:

- collecting larger numbers of cells from small children
- finding ways to get the gene into more cells
- finding better ways of growing the cells
- using collection bags made of different materials

Of the two Clinical Center patients, the first has completed the initial phase of the gene therapy protocol, and the second is almost finished. "Both are doing beautifully," says Klein. He points out that before this protocol is administered to another patient, the two girls must be thoroughly evaluated to see how well treatment has worked and what modifications are needed.

Says Klein, "We know nothing bad has happened, and we have a number of indications that some very good things have happened," but researchers need to see how long those benefits will last without further treatments. Since these repaired cells probably do not reproduce, and eventually die off in the body, both girls will face infusions of fresh cells throughout their lives.

Eventually, gene therapy may be used to treat cancer, infectious diseases, and hereditary diseases other than ADA deficiency. Klein projects that the future of gene therapy is in treating stem cells, permanent cells found in the marrow and bloodstream that produce red and white blood cells. The idea is to insert the missing gene into the stem cells so that the cells they produce will also contain that gene. Scientists here at NIH are working on methods to

## What is a Vector?

A vector, the mechanism for repairing defective cells, is actually a retrovirus whose own genetic instructions have been removed so it cannot replicate itself. The missing human gene is spliced into the vector, which is then mixed with gene-lacking cells taken from the patient. Under carefully controlled laboratory conditions, the vector enters the cell and inserts the gene, thus repairing the cell.

Dr. Harvey Klein, chief of DTM, explains: "The vector carries the human gene into the cell once, but since its defective, it cannot go on to infect any other cells. Once it has done its job, that's it." This contrasts with another retrovirus, HIV, the virus that causes AIDS. HIV enters a cell, controls it, reproduces more of itself, and then infects other cells.

accomplish this. Once that technology exists, DTM would become responsible for collecting, treating, and delivering stem cells to the patient.

Klein knows his team can deliver. The department opened an expanded facility at the west end of the north corridor in August 1990, one month before the protocol began. "This lovely new laboratory gave us the space and physical resources," he says. "We simply could not have done it in the old lab." ■

# On the QT

## *Employee Recognition: A Champion Project*

From birthday cakes to cash awards, it is no secret that most of us thrive on personal and professional recognition we receive from our coworkers and supervisors. TQM emphasizes the role of employee recognition in the process. And, as part of Quality Together (QT), the Clinical Center has established the employee recognition champion project.

A workgroup, composed of a cross section of professional employees and support staff, "is dedicated to developing a recognition program that is meaningful and responsive to Clinical Center employees' needs," says Lawrence Eldridge, employee recognition champion project leader.

The workgroup will use two methods to gather information: focus groups and surveys. The focus groups, made up of 8 to 12 employees selected from a variety of departments and occupations within the Clinical Center, will express their opinions on employee recognition to help learn which individual and group acknowledgments would be most meaningful to the employee.

"We decided to concentrate on the focus group mechanism first," says Gracie Millender, workgroup member. "The focus groups can provide in-depth information within the shortest period of time."

The workgroup is also exploring the best ways to use surveys for collecting additional information regarding employee expectations. They recently polled department heads to learn what forms of employee recognition, formal and informal, are currently being used at the Clinical Center. According to Millender, formal recognition is Clinical Center-wide and is noted in an employee's personnel folder, while informal recognition is department-dependent.

Departments use several modes of formal recognition. For example, the Department of Health and Human Services sponsors an employee-of-the-month award. Some Clinical Center departments have an employee-of-the-month, quarter, and year. "Special act" awards are given to recognize someone for a specific task or event. Promotions, within grade increases, cash awards, and unit awards are other formal means of recognition.

Informal recognition at the Clinical Center ranges from an office party with cake, balloons, and flowers, to something as simple as donuts in the morning to recognize an employee's effort. Luncheons, parties, gifts, and flowers are used to celebrate special events, personal and professional milestones. Secretary's Day and National Nurse Week are often noted with flowers. Promotions, awards,

births, and marriages are also marked in similar ways. Holiday celebrations are other informal means of recognition. In addition, many departments have annual parties, such as awards banquets.

The workgroup also polled outside organizations who have begun TQM for their ideas on recognition programs.

At Rush-Presbyterian-St. Luke's Medical Center, employees nominate managers using TQM criteria for leadership awards. Atlantic City Medical Center grants "pacesetter of the month" awards. The winner of this award is honored at a special dinner and featured in the "pacesetter" column of the company newsletter.

Corning Glass emphasizes non-monetary recognition. Employees at Corning receive individual awards from peers and the TQM team for demonstration of quality. Team awards are given to groups for problem solving and for successful completion of a corrective action. In addition, Corning senior managers personally visit outstanding employees at their work sites.

The Navy Aviation Supply Office in Philadelphia distributes "You Made a Difference" certificates, rewards behind-the-scenes personnel with "Unsung Hero" awards, and offers lotteries for such things as lunch with the boss. ■

# Minor Awarded ASHP Fellow

Dr. James R. Minor of the Clinical Center Pharmacy Department was honored June 5 as a Fellow of the American Society of Hospital Pharmacists (ASHP).

The award, which is part of ASHP's Practitioner Recognition Program, honors sustained practice excellence, continued contributions to the professional literature, and participation in educational endeavors. Other criteria are at least five years of practice in a concentrated area of pharmacy and continued support of the profession through association memberships. Minor,

who has been with the Clinical Center for 10 years, has published extensively. He also edits "AIDS Facts," a regular column in the *American Journal of Hospital Pharmacy*. A member of the editorial advisory board of *American Pharmacy*, he is a frequent speaker at meetings of pharmaceutical associations around the country. He is also a preceptor for the pharmacy residency training program here at the Clinical Center. Minor is one of only 44 pharmacists honored since the award's inception in 1987. ■



Dr. James Minor of the Pharmacy Department was honored as a Fellow of the American Society of Hospital Pharmacists.

## BONE MARROW *Continued from Page 1*

environment to conduct experimental bone marrow transplantation," says Nienhuis. "What makes this unit unique is that it will be highly focused on experimental transplantation and gene therapy."

The bone marrow unit will require a complete reconfiguration of space and will include special air-handling systems and support areas. Personnel will include a coordinated team of physicians, two head nurses, and the involvement of a special-care team.

There will be four special beds for intensive care and cardiac/pulmonary monitoring and 12 beds for general purposes.

"Both areas will have protected access with appropriate filtered air—particularly in the intensive care area," says Nienhuis.

"It will be an awful lot like an

operating room, but nicer," says Roger Mack, Clinical Center hospital administrative officer. A multi-purpose kitchen and a satellite pharmacy will be located on the second floor to accommodate bone marrow patients and their unique needs resulting from drug regimens. The pharmacy will also serve the needs of the surgical intensive care unit on the second floor.

The bone marrow unit is expected to be completed in 12 to 18 months and NHLBI is currently conducting an international search for a director.

"The whole process has gone along well so far," Nienhuis says.

The design of space of the service was clearly a large decision. Credit is due to Hillel Soclof [NHLBI administrative officer] who is coordinating this effort."

"We have insisted on doing things right the first time," says Eldridge. "The attention to detail is incredible. We looked at every single detail. The quality of the environment is critical to the success of the environment."

"We created the unit to anticipate changes so that it has the capacity to support the needs of clinical investigators as clinical care patterns change," states Nienhuis. "We hope this unit will serve the needs in the future very well."

"This unit is going to be a real showcase," says Mack. ■

## Normal Volunteer Program Has Legacy

Brian Kruschwitz, 21, is the son of Dohn Kruschwitz. The two men have more in common than their family name and physical resemblance. Both came to the Clinical Center to participate in the normal volunteer program for a summer during their college careers—almost 30 years apart.

Normal volunteers agree to be controls for experiments in exchange for the opportunity to do research in the labs with Clinical Center specialists. In addition, they



Brian Kruschwitz

are provided with room and board.

Dohn Kruschwitz, now a doctor in Wyoming, participated in the volunteer program during the summer of 1962. He worked in chemistry research. Brian, an environmental science major in his senior year at McPherson College in Kansas, is researching visual memory testing of monkeys.

"The main difference [in the program] from when my father was here and today is the size of the group. When my father was here, there were 50 or 60 volunteers. Today there are about 12," says Brian. He attributes the decrease to the expense of the program and the state of the economy.

According to Brian, his overall experience seems to be quite different from that of his father. Says Brian, "My father was on a protocol that put him on a special diet and required him to stay in the hospital. He couldn't go anywhere—but he learned to sew and knit."

In contrast, Brian has spent a

great deal of time touring Washington, D.C., with other volunteers.

"We have had more than enough free time to go out and do things," he says. "We have seen a lot of the city."

Brian says that although his father had entered the program first, it was his own idea to come.

"I wanted to be in this program for the research experience and the NIH experience. It looks good on the resume," concedes Kruschwitz.



Dohn Kruschwitz

## August Calendar of Events

### 7 Grand Rounds

12 noon-1 p.m. Lipsett Amphitheater  
*Helping Chronically Ill Patients and Their Families Cope*, Sheri Rucker, M.S.W., CC, *The Future of FDA*, David Kessler, M.D., J.D., Commissioner, Food and Drugs

### 14 Grand Rounds

12 noon-1 p.m. Lipsett Amphitheater  
*A Balanced View of Vestibular Disorders*, Robert Lebovics, M.D., NIDCD, *Radiation Oncology: Everything You Wanted to Know But Were Afraid to Ask*, Eli Glatstein, M.D., NCI

### 21 Grand Rounds

12 noon-1 p.m. Lipsett Amphitheater  
*AIDS Update*, Anthony Fauci, M.D., NIAID, *New Research Concepts in Stroke*, Michael Walker, M.D., NINDS

### 22 "The Human Genome Project"

10:00 a.m. Lipsett Amphitheater  
A video produced by the National Center for Human Genome Research. For more information call Sandy O'Connor at 402-0911.

### 28 Grand Rounds

12 noon-1 p.m. Lipsett Amphitheater  
*Oxygen Radical-Mediated Inactivation of Enzymes: Biological Implications, Myositis: Old Problems and New Patterns*, Paul Plotz, M.D., NIAMS